



**UNITED PORPHYRIAS**  
ASSOCIATION  
Advancing Awareness, Research & Therapies

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## The Future of Porphyria



Be sure to SIGN UP on  
[WWW.PORPHYRIA.ORG](http://WWW.PORPHYRIA.ORG)  
to receive important news, information, and  
updates on the porphyrias!

Sign UP Today!

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**Rise UP. Speak UP.**

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### SCIENTIFIC ADVISORY BOARD

The [UPA Scientific Advisory Board](#) is comprised of world-renowned porphyria experts. Their individual and combined decades of experience

are available to support you and your care management team!

### Peer-to-Peer Consultation

Does your local physician need support with your care? Reach out to UPA so they can access the support of an expert porphyria doctor.

### What's Up Doc – Question of the Week

Each week, a member of the UPA Scientific Advisory Board will answer a question about porphyria! This is your opportunity to get a response to your questions – big and small. Recent weeks shared information about [PAIN](#) in the porphyrias, [HOMOCYSTEINE](#) in [AHP](#), and [IRON](#) in [EPP](#).

### Publications

See [www.porphyrria.org](http://www.porphyrria.org) for "Spotlight" studies along with a full list of Porphyrias Consortium [publications](#).



### EPP INTERVIEW RESEARCH STUDY



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Do you have Erythropoietic Protoporphyrria (EPP) or X-linked protoporphyria (XLP)?

Interested in participating in Zoom interview?

We are seeking ~ 20 adults and adolescents with Erythropoietic Protoporphyrria (EPP) or X-linked protoporphyria (XLP) in the US and

Canada who are at least 12 years of age and speak English.

If you qualify for the study, you will be asked to participate in one Zoom interview that will last **no more than one hour**.

Each interview will be scheduled at a time that is convenient for you, including during the day, during the evening, or on weekends and will be conducted by a member of a project team.

After you complete the interview, you will receive a **\$150 Amazon gift card** for your time.

Email [info@porphyria.org](mailto:info@porphyria.org) or call 800-868-1292 to participate!

**STUDY NOW OPEN FOR ACUTE HEPATIC PORPHYRIA  
(AHP) REPORT ACUTE ATTACKS RELATED TO  
MEDICATIONS!**

The NIH-Supported Porphyrias Consortium has launched an online

## NEW STUDY IN AHP



**YOUR PATIENT  
EXPERIENCE IS  
NEEDED!**

STUDY NOW OPEN  
FOR  
**ACUTE HEPATIC  
PORPHYRIA (AHP)**



observational study to collect information on acute porphyria attacks that may have been caused by a medication. The “Evidence-Based Assessment of Medication Sensitivity in Acute Hepatic Porphyria” requests patient and caregiver reports on suspected medication/drug-induced acute porphyria attacks, as well as safe use of drugs previously labeled “unsafe” or with unknown risk.

The goal of this project is to create an updated list of medications that are risky or safe for people with one of the acute porphyrias.

After consenting, participants 18+ will be provided a unique web link to complete the initial survey. Participants will be encouraged to update their surveys when they have new information to report.

To participate, please contact **United Porphyrias Association** on [info@porphyria.org](mailto:info@porphyria.org) or call 800-868-1292.

[ACCESS OTHER ONGOING RESEARCH STUDIES HERE!](#)

## COMING SOON!

**PORPHYRIA  
AWARENESS  
WEEK 2022**

**GLOBAL AWARENESS  
EFFORT**

Get out your  
**PURPLE** and prep  
for **Porphyria  
Awareness Week**  
– April 2-9, 2022!

**PORPHYRIA**  
*Awareness Week*

**PORPHYRIA  
TOGETHER**

APRIL 2nd-9th, 2022

**UNITED PORPHYRIAS  
ASSOCIATION**  
Advancing Awareness, Research & Therapies

**DONATE**

